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Balancing Innovation and Responsibility With Citizen Data: A Case of Wellness Records

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Abstract

In the age of the data and artificial intelligence, the data itself has become as the fuel of new innovations, improvements and prosperity. However, in the domain of healthcare and citizen-based personal data, the regulation and freedom of usage have been naturally remarkable more controlled than in the other domains. This study takes a look on the domain where the information considered is personal data, yet its secondary usage is not regulated as strictly as, for instance, personal health records. The case of wellness records is used as an exemplar case as it falls between these ends. This study contributes to this discussion of ethical data economy by emphasizing the point of cultivating or preventing innovations in the usage of data. While a majority of the extant literature focuses on the aspects of control and freedom, this study emphasizes also the potential for new innovations that the data could offer. Yet, this needs careful balancing between innovativeness and responsibilities.

Keywords

Data economy, Fairness, Innovation, Personal Data, Responsibility


1. Introduction


The modern time in the business world is often described as the *era of data*. Here, data has been argued to become as the fuel, the new oil, of new economic growth and prosperity [1]. Data collected from various sources can be used to create completely new products and services, or improve the efficiency of the current ones. Therefore, the possibility to use data in various industrial as well as in governmental domains have gained lot of interest previously. Thus, the new era ‘data citizens’ are producing data that has become a powerful tool both both in politics as well as in the industrial markets [2].

For the sake of discussion in this paper, we simplifying the discussion by categorizing data into two main groups: (i) *personal data*, that is data consisting of, or containing identifiable personal information [3]; and (ii) non-personal data. In the former group, there are various subcategories ranging from the patient health records to the GPS locations of a vehicle transported by a identifiable person. In the latter group, there are all data which cannot be linked to a person, or does not contain any person specific attributes. For instance, a longitudinal data of a machine’s vibration does not contain any personal information.

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While this categorization oversimplifies the rich variety of data which is collected and used in the society, it helps to illustrate ethical questions related to the usage of data, especially that kind of a data which is collected from or contains person related attributes. As stated, the data has been seen as the fuel of innovations for the new era and In the European Union (EU), the General Data Protection Regulation (GDPR) [3] is a comprehensive privacy regulation for personal data, which was adopted by EU in 2016 and went into effect on 2018. The GDPR includes strict rules for data controlling and processing, and imposes severe penalties for non-compliance of the regulation, including fines of up to 4% of global revenue of the organization or €20 million (whichever is greater).

In Finland, an EU county, the use of customer and patient data – which can be generally considered as the arch-type of the personal data – is a strictly regulated activity [4]. However, the public sector has invested in the development of artificial intelligence and data analytics to make it possible better public services and experimented with the use of artificial intelligence to find potential risk factors for exclusion. Examples of this are the city of Espoo's artificial intelligence experiment [5], where data from the public sector was combined and extensively analyzed with the help of artificial intelligence, so it was possible to predict risk factors related to child welfare clients. Another example comes from the South Karelia hospital district, where machine learning methods were developed to predict the social exclusion of young adults [6]. In this case, the legislation on the secondary and combined use of healthcare data was followed, which only allows the use of de-identified, pseudonymized data.

As these examples illustrate well, the data science and artificial intelligence tools can be used for the greater good of the society. However, not all such initiatives have ended well. For instance, *toeslagenaffaire* refers to a Dutch scandal caused by a self-learning algorithm, which falsely claimed several citizens for child care fraud, ultimately leading to several suicides due to the collection of claimed fraudulent allowances [7]. Similar reports from the use of algorithms for automatically detecting welfare frauds and their ultimate consequences have been reported also from USA [8].

In Finland, the secondary use – i.e., the use of a data in the purpose where it was not initially collected [9] – of health and social care data is regulated by law, with interpretation rules and regulations regarding the use of social and health care registers and documents for research purposes [10]. Citizens can enter their wellbeing data in Kanta PHR – a national personal health records (PHR) service of Finland – using wellbeing applications and measuring devices developed for such purpose. Currently the wellbeing data is for your personal use only. In the future, the Client Data Act will enable you to give your consent to sharing your wellbeing data with healthcare and social welfare professionals [11].

Although the person has comprehensive well-being information in the Kanta PHR system, the person cannot share it with service providers, which makes it difficult to develop new services that utilize well-being information. Furthermore, typically in the practice, difficulty here is the location of the data in different data reserves and systems. Although the organizations use the same information systems, the information systems are customized for each organization, which means variation in data structures and interface [12]. These, together with overall innovation climate, might prevent or hamper the born of *new innovations*. While the ethical discussion on the era of data is diverse, the focus has mainly been on the rights of a citizen. This study contributes to this discussion on the possibilities, as well as the hindrances, of the data usage by

emphasizing the role of innovations and innovation climate for the creation of new services and goods.

2. Background

2.1. Innovation

For over a hundred years, initiated by the work of renowned economist Joseph A. Schumpeter [c.f. 13], *innovations* have been seen as one of the critical aspects of economic growth and change [14]. Schumpeter argued that technological innovations often create ‘temporary monopolies’ which are remarkably profitable for their owners. However, this advantage would ultimately diminish as the competitors and imitators enter the market. [14]

International Organization for Standardization (ISO) defines in their standard [15] ‘*innovation*’ as a “*new or changed entity, realizing or redistributing value*”. This definition makes a difference between an idea or invention, and an innovation – the latter emphasized the economic or societal impact of the new idea. However, there are various different views what constitutes an innovation and what not. For instance, Edison et al. [16] found in their literature review 41 different definitions of innovations.

However, to follow an old adage, innovations ‘*does not grow on trees*’. It is argued that it requires more than just resources and discussions to become an innovative company, often emphasizing such concepts that innovation climate and culture [17]. As illustrated by Ahmed [17], an anti-pattern for innovation and creativity is an organization where the importance of innovations are discussed among the top management, yet the only visible effort is infrequent investments in research and development work. Contrary, Agile software development methods have been argued to drive innovativeness of an organization—compared against the use of plan-driven methods—[18], which might be linked to the elevated climate of innovation in the agile teams [19].

On a large picture, the model by Tidd and Bessant [20] identifies five constructs of a company driving for its innovation activities: (i) strategy, (ii) process, (iii) organization, (iv) learning, and (v) networking. While there is some empirical support for the T&B model [c.f. 21], it remains overtly abstract for understanding the forces creating an innovative organization. Therefore, in the following we focus on an organization’s internal attributes thriving for innovations, namely in innovation climate and culture.

While there are – again – multiple different definitions for an ‘*innovation climate*’ [22], it is often defined as a shared perception of the extent which a team’s (or an organization’s) processes encourage and support innovation [23, 24]. Ekvall [25] has studied the different dimensions of innovation climate and listed high-level factors that enhance favorable environment for the innovations. In his model, the factors constituting towards innovation climate factors [25]: (i) challenge, (ii) freedom, (iii) idea support, (iv) trust/openness, (v) dynamism/liveliness, (vi) playfulness/humor, (vii) debates, (viii) conflicts, (ix) risk taking, and (x) idea time.

In addition to the innovation climate literature, the research stream focusing on innovation culture has been identifying factors enhancing innovativeness. While innovation climate describes how the members of an organization perceive it by different processes, practices

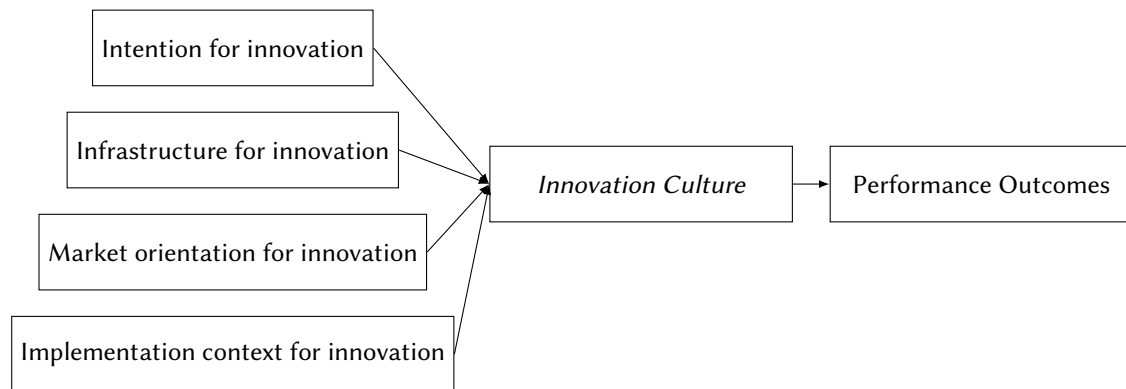


Figure 1: The dimensions of Innovation Culture according to Dobni (adopted [26]).

and rewards – or otherwise stated, what are the real priorities of the organization towards innovation. Innovation culture then again reflects on the deeply held values and beliefs towards innovation in the organization. Thus, innovation climate is to some extent observable by the different practices and rewards, innovation culture reveals how the members of organization are reacting to different incentives as they aim to act according to the organization’s culture. [17]

For instance, the model by Dobni [26], c.f. Figure 1, illustrates four different dimensions of innovation culture. Constructs, building up the different dimensions of the model, contain such aspects as organizational constituency and learning. Whereas the innovation climate factors by Ekvall [25] emphasize humane aspects such as trust, debates and humor, the innovation culture model by Dobni [26] aims to measure more deeply hold beliefs of the organization. Finally, as have been discussed in the context of organizational culture and organization climate [27], while the borders of these two concepts are clear in the conceptual level, in practical level the measures might often be mixed.

To summarize, the innovativeness of a company is built—and respectively destroyed—in multiple levels, starting from the deeply hold beliefs (innovation culture), to the perceived practices and rewards (innovation climate), as well as the strategy and innovation supporting processes of an organization (T&B model). Merely held belief that an organization is against of benefiting personal data for new innovations due to, e.g., the GDPR legislation and possible fines, might stifle the born of new ideas. Yet, as discussed in the introduction, there are positive examples [5, 6] from the innovative usage of personal data to generate value for all.

2.2. Related work

Prior works have covered multiple aspects related to the usage of personal data. For instance, emerging efforts by the companies – such as MyLife Digital, MyData Global or DigiMe, which are also called as a form of *data activism* [28] – empower individuals to control how their personal data is potentially used [29, 30]. In these models, one challenge is related to the accountability of data usage. Over the time, situations change and previously given consent to transfer data to the services is no longer necessarily valid, in which case a mechanism is needed to remove data from the services.

This domain's ethical discussion, in the extant literature, has mainly been focused on the fair and people-centered design and use of the data. Couldry and Mejias [31] even compared the current practice in the data industry to historical colonialism. In similar vein, Sadowski [32] argues that data should be considered as a capital which is produced by extraction. Thus, for instance Koskinen et al. [33] argue that in the creation of new kinds of data ecosystem, a human-centric approach should be utilized. A similar call has been presented for biomedical data [34]. In their work, Knaapi-Junnila et al. [35] requested of taking the citizens into the discussion of the data's usage. Koskinen et al. [36] further formulated this approach into a discourse ethic -based tool.

In study by Rantanen [37], control over the data – among with the transparency and security – was found as one of a European basic values in the data economy. In their further work, Rantanen et al. [38] argue that these European basic values in the data economy are ethically justifiable.

3. Analysis

This study is building up an argument that the current actions inside the EU, as well as in Finland, are holding up the innovations in the usage of personal data. That is, the overall actions are likely hindering the capabilities of new emerging innovations to born in the sector of wellness records. As illustrated by the few given examples [5, 6], the secondary usage of personal data has been able to achieve ethically justifiable, positive results.

While the use of patient health records is highly regulated and monitored, the case of more general wellness records is not that clear. The sector is not that heavily regulated by EU regulations or national laws, yet the information handled is personal data and under, e.g., GDPR regulations. Therefore, in the domain of wellness data applications, there could be space for new innovations, which would benefit individual as well as society at large. However, the overall actions might create atmosphere against innovations in this domain.

As discussed in the review of innovation drives in an organization, innovativeness is not built just on declaring it as a company's value or founding a reward programs for new ideas. Instead, it is an end result of holistic approach towards new ideas and innovations.

In the following, we will discuss about the main issues identified, which are hampering the innovativeness in this domain:

Fear of GDPR. Even large corporations, in the Nordic countries, seems to be afraid of GDPR. In a study by Hyrynsalmi et al. [39], the authors interviewed large embedded-systems companies on their developing data business activities. The study discussed that even the large companies, studied for the paper, are cautious in their new innovations due to the fear of GDPR. While also the GDPR fines for large companies are remarkably larger than for a startup or a medium-sized company, it can be argued that the similar cautious atmosphere regarding the usage and storing of data which would contain personal information is also prevalent in all companies. As discussed previously, these kinds of deeply holds beliefs act against innovativeness.

Unclear future prospects. The legislation in the EU regarding the use of data is currently

evolving heavily¹. For instance, Data Act (DA) [40], Data Governance Act (DGA) [41], and Digital Services Acts (DSA) [42] are new regulations put forth by the Council of European Union. These are all parts of new actions prepared by the EU to curb the digital markets. Whereas some of the regulations have already been set, some of them are still under construction. However, while these new directives are likely to serve good purposes and suit the improper usage of data in the markets, they will likely have impact by hampering the innovativeness.

Lack of incentives for a citizen to share the data. In the current setting used in Finland for sharing wellness data, there is little if any incentives for a citizen, a user of the potential new systems to share his or her data with the third party developers. In current system one gets product benefits (lower price, additional features) by giving consent to use the data which in longer term might lead to lock-in. Whether this is true problem is unknown in the advent of innovation practises in this space. *Fair data economy* has been suggested as the solution [43], as it would allow the users also to benefit from the data their are giving. However, there is still a lack of, direct as well as indirect, benefits that the user would receive of sharing his data willingly with third-party developers. This is even more evident in the case of startups and new players in the markets as they cannot benefit of luring the users to share their data as some larger actors could do.

Unclear and uncertain responsibilities in the era of AI. As often is with data, different machine learning (ML) and artificial intelligence (AI) solutions can be expected to be in a central role in the near future in the creation of new innovative product and services. However, it is considered that AI itself cannot be held responsible for its actions [44]; yet, some form of a group liability has been proposed as a solution². Nevertheless, the open question of liability and responsibility in the results of AI's or ML's decisions might hinder the application of these techniques in the domain wellness records. While the forthcoming Artificial Intelligence Act (AI Act) [45] and AI Liability Directive [46] by the EU is likely to suit the use of the AI technology; however, before they have become effective, the uncertainty towards the future might act against the innovativeness in this domain.

4. Discussion & summary

While there is no doubt that GDPR legislation has worked well in securing personal data and preventing misuse in several occasions, it is also acts against the innovativeness of the data economy field in Europe. The benefits from the directive likely surpass the negative consequences; however, innovations can bring good for individual and society alike. Therefore, for cultivating a fruitful environment for innovations, preventing actions are needed.

Some technical solutions to support the fair data economy, as discussed earlier, exists. For instance, a blockchain -based authorization solution for sharing as well as controlling who uses the data – thus also allowing monetization of the data for its initial collector – could potentially

¹The Digital Decade website by Hannes Snellman Attorneys Ltd has collected the forthcoming changes and illustrates well the various different directives as well as regulations pushed forward by the EU. <https://digitaldecade.hannessnellman.com/>. Last accessed August 10, 2023.

²T. Kalliokoski (2023). Tekoälyn vastuuta voi verrata ryhmävastuuseen. <https://etairos.fi/2023/02/21/tekoalyn-vastuuta-voi-verrata-ryhmavastuuseen/> Last accessed August 10, 2023

tackle some of the presented hindrances. However, a platform like this would also create new problems, especially regarding the responsibility and question regarding the maintenance and use of the system. This question largely depends on the type of data used. In case of personal data one can claim the responsibility never ends. In the case of anonymous data one can assume the quality of the data determines the actual lifecycle of it.

In addition, the class action lawsuits pending in the United States [47]. regarding the relationship between artificial intelligence and copyright, may affect the entire artificial intelligence industry. While the result would not directly affect into the companies working in the EU, some of the existing solutions and platforms are offered by the USA -based companies.

However, it is worth to note that the premises of this study should be critically analyzed, too. For instance, Brey [48] argues that privacy has only instrumental value in a good society augmented with technology. According to his reasoning, only well-being and justice are intrinsic values, and therefore privacy should be evaluated against these. Thus, the problematization presented in this study, as emphasized also in the title, calls further ethical discussion.

Finally, it is worth to note that GDPR-compliant data economy products and services could be of competitive advantage in the global market, where the privacy and proper usage of personal data have been constantly gained more attention. Therefore, cultivating the innovative culture in the European data economy could create globally remarkable new solutions.

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